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## **A nurse-led sleep service for children and young people with disability**

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## **Abstract**

This article discusses the outcomes from a nurse-led, community based sleep hygiene service for children and young people. The sleep hygiene service was designed and implemented within a Community NHS Trust. The project aimed to provide evidence for wider roll out of such a service within the Trust.

This project recruited 22 participants into an 8 week programme over 6 months and collected both quantitative and qualitative data. Quantitative data included quality of life impact of the child's sleep problem on the carer and family unit pre and post intervention, along with service cost. Qualitative feedback through expectations and experience was also collected.

The programme showed a significant and positive impact on quality of life measures  $p=0.003$ , with two thirds of participants achieving 40% of their expectations by the end of the 8 weeks. Parents expressed that they felt 'less helpless' and valued the support within the home setting.

Cost and benefit analysis showed that the service could reduce costs associated with high cost prescriptions but also positively impact on Community Paediatric waiting lists and clinic appointments.

## **1.0 Introduction**

The incidence of sleep disturbances in children both generally and with complex disorders such as ADHD and neuro-disability are widely documented (Bruni & Novelli, 2010; Jan et al, 2008; (National Institute for Health and Care Excellence [NICE] & Social Care Institute for Excellence [SCIE], 2013). Such problems can have significant impact on physical, psychological and social development and educational engagement. If this is poorly managed it can have considerable effects on long term health and wellbeing into adolescence and adulthood. Sleep disturbance can also lead to increased levels of stress and pressures on parents/carers, the family and educational environment; worsening family difficulties, which can compound the sleep problem further but also impact on their health

(Jan et al, 2008; Meltzer & Mindell, 2007; LeBourgeois et al, 2005). Sleep hygiene is considered to be practices or actions and the environment in which one prepares to and goes to sleep; night time routines. Therefore, 'good' sleep hygiene should result in effective sleep. It is known that good sleep hygiene practice and quality of sleep for school age children and young people is linked; with the promotion of 'good' sleep hygiene practice in the home shown to improve sleep patterns and sleep quality (Sun et al, 2012) however, a systematic review has identified that there is still limited research evidence published in this field, particularly for nurse led, home based services (Vriend et al, 2011). Other literature suggests a need for further evidence supporting the use of therapeutic and behavioural approaches in managing sleep disturbances in children and young people (NICE & SCIE, 2013; Malow et al, 2012). Furthermore, Jan et al (2008) highlight the need for adapted sleep hygiene practices for children with disabilities and recognises the challenge of implementing such intervention. This suggests a possible need for interventions which provide more intensive support, in the home setting; making interventions practical and individualised

Treatment guidelines for children with general sleep problems and complex disorders suggest the use of medications of which the long term effects are not well researched and are most effectively used in combination with non-pharmacological sleep hygiene interventions (Bruni & Novelli, 2010; NICE & SCIE, 2013; Bendz & Scates, 2009). In addition, medications recommended for use for this purpose are of high cost to the NHS (National Health Service) and it is complex to monitor prescribing activity related to these needs.

In the context of this project, local hospital based services for sleep disorders are more adult focussed and therefore do not meet the needs of the child with complex disability, this also does not provide care close to home and is less likely to engage those from disadvantaged backgrounds. Many of the children with ADHD and other such conditions are already known to Advanced Nurse Practitioners, Specialist ADHD Nurse and Consultant Paediatricians but general community clinics do not offer [or have capacity], the time and resources needed to assist in monitoring and management of sleep disorders which are often a lead cause for exacerbation of educational and social difficulties.

We are also aware that there is a shortage of general paediatric sleep services across the United Kingdom, resulting in unnecessary or inappropriate referrals to specialist secondary care or mental health services.

The Children's Specialist Disability Service [CSDS] is a nurse-led team of community based Health Visitors [HV] and Healthcare Assistants [HCA], providing a range of support to children and young people from 0 to the age of 19 years who have disability of any kind. The service also offers a range of support to carers and the family unit; focus is on personalised, collaborative and integrated care. It is proposed that with current evidence, clinical guidelines and government agenda that a community, home based sleep hygiene support within CSDS will strengthen primary-secondary care functions, provide more personalised care and support; enabling patients to be seen by the 'right service, at the right time.' (Department of Health, 2012) This paper outlines a pilot project evaluating such a service.

### *1.1 Aims & Objectives*

- To Improve health outcomes for children with a disability and sleep problems [and their families] in the community setting

- To evaluate the impact of a service development initiative in a children's disability service for children with sleep problems
- To begin to evaluate the cost of a nurse-led, home based sleep hygiene service compared to current provision
- Make recommendations for future practice/service provision

## 2.0 Methods

This was a mixed methods pilot project, gathering both quantitative and qualitative data [with a focus on quantitative measures] which implemented a nurse led sleep hygiene intervention in the home setting, as part of the CSDS. The programme was led by a Research Manager and CSDS Lead Nurse and clinical delivery was carried out by the CSDS Nurse Lead, a Specialist Health Visitor and one HCA. The HCA was practicing in Agenda for Change (AfC) salary Band 3, which is a typical salary for a non-professionally qualified member of NHS staff (NHS Staff Council, 2013). All had all completed the Handsel Trust Sleep Practitioner training programme. This is a nationally recognised training programme, specifically intended to equip professionals with underpinning knowledge around sleep theory and specialist skills to support children with disability and their families (Handsel Project). It aims to ensure consistency in service but was undertaken so that the pilot project interventions were evidence based.

### 2.1 The Intervention

The eight week programme was intended to be highly personalised to the child, young person and family unit. It consisted of one initial home based assessment by a member of the project team which intended to assess the characteristics of the sleep problem, understand the home and family environment and begin to identify possible changes and adaptations that could be made within this in order to improve sleep patterns. Examples of advice and sleep hygiene practices can be found in diagram 1 [examples taken from Early Support Programme, 2010].

*Insert diagram.1*

Six follow up visit on a weekly basis [where possible] were carried out, where actions from previous sessions were reviewed and adapted [where required], along with new ones being set.

Parents/carers were required to complete a weekly sleep diary and ABC [Action, Behaviour, Consequence] sheet which outlined any problems which were encountered, and the parents/carers response to these (Early Support Programme, 2010; Handsel Sleep Practitioner Training). This aimed to identify possible interventions to improve the environment or behaviour management. The sleep diary also outlined how often the child or young person woke up, got out of bed, how long they slept for and when during the day they slept.

Finally, an eighth visit was carried out where the whole programme was reviewed and advice for going forward was provided. Here, referrals may have been made to other services within the NHS trust, or parents were provided with details of how to contact the service again if required.

### 2.2 Sample & Sampling Frame

Children and young people were referred into the CSDS from the Community Paediatrics Consultant Team over a 4 month period. Eligibility was assessed by the CSDS Nurse Lead. An estimated 20 families were expected to be recruited into the programme.

For eligible children [inclusion criteria can be seen in Figure.1], weekly home visits were provided by the Children's Disability Team and 'good sleep hygiene practice' was assessed and promoted as described previously. The allocated team member would then review progress to date and make a joint action plan for the following week.

*Insert figure.1*

### *2.3 Data Collection*

As part of the programme parents were asked to complete a Handsel Trust sleep diary and Action, Behaviour, Consequence (ABC) chart. A data collection tool incorporating baseline measures of demographic data, disability, diagnostic status and data relating to the identified sleep problem and previous interventions was developed by the Project Lead, reviewed and adapted by the clinical team. There was particular interest in the previous use of Melatonin or pharmacological interventions and whether these were deemed to be effective. The data collection tool also included the home based baseline assessment carried out by the nominated Children's Disability Nurse.

Data collection tools were adapted over the first month in response to clinical teams and parent experience of the project to optimise time spent with parents and children, but also to enable purposeful data to be gathered. Staff time spent [face to face, telephone and documentation] and mileage travelled was also recorded to inform future recommendations for the service.

An adapted paediatric/family quality of life questionnaire similar to Pediatric Quality of Life Inventory (PedsQL), using Likert scores of 1-5 was used to gather baseline and post intervention impact on the main carer and family unit. The adaptations were

1. Consolidation of a family and parent/carers assessment of quality of life statements; to assess both the individual impact and the family unit quality of life and,
2. The Likert scores adapted the scoring system currently in use with PedsQL but made it simpler for the team and parents to discuss together and complete as part of the programme, without taking too much additional time from the assessment process

In addition, parent expectations were determined pre and post intervention, and qualitative responses regarding the perceptions of the sleep programme were documented.

Where there may have been extenuating circumstances which could have impacted on the results of the programme, these were also recorded within qualitative data.

### *2.4 Data Analysis*

Descriptive statistics of mean, median and standard deviation were used to analyse staff time spent on project work, along with evaluation of costs associated with the project. A local 2012-2013 Trust costing template was used to draw up costs associated with current service provision and the cost of

Melatonin prescribing along with national prescribing guidelines. Currently, no sleep hygiene services were provided within the trust; this project evaluated:

- the costs of staff, travel and expenses of providing the nurse-led service,
- the number of participants and cost prevented from requiring melatonin to control their sleep problems compared to the current Melatonin costs within the trust
- if the nurse-led service provided value for money compared to a consultant outpatient clinic [current standard]

The statistical software programme SPSS 19.0 was used to record and analyse per protocol quantitative data collected, along with content analysis for any qualitative comments made by parents. Data normality was assessed through a Q-Q plot.

Paired sample T-test to the 99% confidence interval were used to evaluate pre and post programme quality of life scores and a one sided independent T-test to the 99% confidence interval was utilised to identify if quality of life scores improved and if parent/carer expectations were met by the programme. Kruskal-Wallis and Mann Whitney-U tests were used to establish any significant relationships between categorised data and quality of life scores.

Where parents did not complete the programme, no data regarding the sleep disorder was recorded or collected for the purpose of this project. However, demographic data and the reason for non-completion were recorded.

## *2.5 Approvals*

Approvals for this service were sought from the Senior Management Team and Clinical Governance Group as this project was considered an enhanced evaluation project and did not require healthcare ethics approvals. All data was stored in accordance with Trust policy and procedure and a final report was provided to both approving groups. Confidentiality of participants was maintained by using unique participant identification numbers on all evaluation documentation.

All participants provided informed consent before entering the project and were able to withdraw at any time without providing a reason.

## **3.0 Results**

### *3.1 Quantitative*

14 Children completed the programme with 8 who did not complete. Reasons for non-completion are discussed in section 3.2.4.

#### *3.1.1 Demographics*

The age ranges of children completing the programme are shown by way of a boxplot in Figure.2. The mean age of participants was 5.46 years s.d. 3.35, median 5.0, the eldest was 12 and youngest was 1, and interquartile range showed that most participants were within the age range of 2.5-8 years. A Q-Q plot determined that age was not normally distributed.

Of the 14 participants 71% [10] were male and 29% [4] were female.

All but one female participant had English as a first language. This participant declared themselves in the 'Asian' ethnicity category, with the rest in 'White'.

### *3.1.2 Sleep specific data*

All participants had experienced their sleep problem for over of 12 months.

### *3.1.3 Previous Interventions*

Of the 14 participants who completed the programme, 50% of parents had tried at least two other interventions to manage their child's sleep disorder, with 29% having used at least 1 alternative. Other interventions suggested included:

- Ignoring: trying to ignore the child asking for their parent or ignoring them moving about in bed
- Alarm systems: systems which can be placed on the floor next to the bed, or on the door handle and will alert parents if the child/young person gets out of bed
- Controlled exit/withdrawal
- Gate on bedroom door to prevent the child or young person wandering around the house, getting into their parents bed or getting up to watch television or play on computer games
- Sitting with the child whilst they settle and go to sleep
- Pharmaceutical interventions such as Melatonin

A Kruskal-Wallis test showed no significance between previous intervention use, achievement of expectations or impact on quality of life outcomes.

### *3.1.4 Melatonin Use*

5 parents had used melatonin as an alternative treatment in the past, most [all but one] reporting no effectiveness. The one parent who responded 'yes' to melatonin effectiveness then went on to identify that 'settling' was the problem rather than not sleeping continuously.

Mann Whitney U testing showed no significance between previous Melatonin use and achievement of expectations, or quality of life impact associated with the programme.

### *3.1.5 Pre and post impact on quality of life*

On the quality of life questionnaire a maximum score 110 could be achieved. A higher score correlated with a lower quality of life and possibly higher impact of sleep on carer and family unit.

12 of the 14 [86%] participants had a reduced score on the quality of life impact assessment; suggesting that the intervention improved quality of life for the carer and family unit.

Paired samples T-testing at 99% confidence interval showed  $p=0.000$  CI[10.107, 41.464] df 13.

Baseline quality of life measure had mean = 75, s.d. 10.961

Post programme quality of life measure showed mean = 49.21, s.d. 20.599



This illustrated that quality of life post programme was significantly improved to the 1% confidence level.

A one sample T-test was carried out with a 99% confidence interval to test the hypothesis that there was an increase in quality of life score pre-post intervention;  $p=0.001$  CI[-.04475, -0.0640] df 13. This confirms that the intervention increased quality of life to the 1% confidence level for at least 60% of participants.

No significance was found between gender, number of previous interventions or number of baseline expectations and quality of life score.

### *3.1.6 Participant Expectations [e.g. improved sleep, improved behaviour]*

The number of expectations pre programme was recorded, and post programme with the number of expectations which had been met; with a maximum of 5 given for each participant. Of the 14 participants, 9 [64%] had **all** expectations met; only 1 participant said that no expectations had been met.

A one sample t-test was used with a 99% confidence interval to test the hypothesis that at least 60% of participants had at least 40% of their expectations met over the course of the programme.  $p=0.003$  CI[-0.642, -0.548] df 13 showed that this was achieved to a confidence level of 5%.

### *3.1.7 Time Spent*

The mean time spent by staff in total [including service evaluation documentation] was 15.77 hours; 8.2 hours were spent on face to face contact. A mean 4.02 hours was spent travelling to and from participant's homes.

There was no correlation or statistical significance found between times spent in total, or time spent on face to face visits and the quality of life impact. There was also no statistical significance between the age or gender of participants and time spent.

### *3.1.8 Cost of intervention against 'standard' care*

Whilst this service was provided by a range of staff AfC bands, the mean cost of the intervention was based on the **addition** of a Band 4 HCA to the current CSDS team. This would provide an additional member of staff for 80% of a full time equivalent based on current CSDS demand and staffing capacity. A Band 4 is considered to be an autonomous, skilled, and experienced and/or foundation degree qualified HCA or Assistant Practitioner [AP].

For each child, time spent on the activities associated with this service, along with mileage at 42.5 pence per mile was calculated. The mean total cost per participant £201.24, s.d.60. Comparatively, the cost associated with Melatonin prescription over the course of a year was obtained (Leicestershire Medicines Strategy Group, 2012; National Prescribing Centre; UK Medicines Information, 2008; NHS Business Services Authority, 2013): Tablet £345per year; Liquid av. £809.75 per year. According to clinical guideline sleep interventions such as this initiative should be implemented prior to prescribing Melatonin. However, from this sample 36% of participants had already tried Melatonin as an intervention.

#### *3.1.8a Melatonin*

The mean total cost comparison against the minimum £345 per year and for the maximum £809.75 per year for a child prescribed Melatonin, showed that the cost of the sleep service [per participant] was significantly lower  $p=0.000$ , mean difference of £143.75;  $p=0.000$ , mean difference £608.51 respectively. If each child [from this cohort  $n=14$ ] required an annual review in accordance with local and national guidance (LMSG, 2012) this would add a **minimum** approximate cost £450 in addition to the medication cost.

#### *3.1.8b Consultant Time*

If this caseload of children had remained under Consultant Community Paediatrician care, with an average 4 consultations required per participant over the course of 12 months; this would equate to an average cost of £2027.20 overall [for this cohort only] without quantifying impact on Community Paediatric waiting lists.

From electronic patient records it is estimated that a minimum of 100 children would be served by a widely implemented service over one year. If 100 children/young people were under the care of a Consultant Paediatrician for a sleep disorder, requiring an average 4 visits [including 1 assessment] this would equate to an approximate cost of £14,500 to the service in Consultant time alone.

#### *3.1.8c Melatonin & Consultant time versus Sleep Management Service*

Based on 100 children requiring an average of 4 Consultant OPAs and then 32% prescribed Melatonin over 18 months this would result in £31,290-£46,162; dependent on the prescribed formulation. From this project it is proposed that a 0.8 Whole Time Equivalent (WTE) AfC Band 4 to

support wider roll out would cost approximately £32,974 including overheads (such as superannuation and national insurance).

Assuming a success rate of 91% calculated using completed participants and onward referrals/outcomes from non-completing participants in this project. There may also be the added advantage of reduction in Consultant clinic time needed to attend to sleep disturbance problems but also a potentially positive impact on waiting lists.

### *3.2 Qualitative Data*

#### *3.2.1 Parental Expectations*

Expectations from parents that were met by the programme can be viewed in diagram 2:

*insert diagram.2*

#### *3.2.2 Feedback Comments*

Seven key themes were identified from qualitative feedback from parents identified the key benefits of the sleep service

1. high quality support
2. improved structure in bedtime routine and family organisation
3. home visits are the 'right' approach
4. parents sleep is improved
5. child/young person's sleep is improved
6. child/young person's behaviour is improved
7. relief that Melatonin would not be required

Parents highly valued the home-based and family centred support that was provided and felt less helpless following the programme intervention.

There were reports that parents felt they had developed the skills in which to deal with any sleep disturbances in the future if they were to arise along with relief that they would not require pharmacological interventions suggesting potential for longer term impact of the programme.

*"Mum says that at the beginning she was sceptical as to sleep programme working, but has time has gone on she has seen a light at the end of the tunnel. Mum says xxx is calmer during the day. Mum says she is extremely happy she has not had to resort to Melatonin."*

*"Parents are very happy and sleeping better themselves and xxx sleep improved almost immediately. Xxx is in a lovely mood and loving his bed. Parents say that they have found the process extremely helpful and do not feel helpless now as they know what to do. They are hopeful that they won't have to resort to Melatonin."*

All parents commented that they would recommend the service to others and that it should be offered to others who are eligible.

*“I would recommend this service to other families who are struggling. We knew we had to change things but didn’t know how to...I have appreciated the support... home visits were the right approach for us”*

### *3.3 Demographics of Participants who did not complete the programme*

The mean age of those who did not complete the programme, 8.5, sd 2.78.

A Mann-Whitney U test to the 95% confidence interval showed no significant difference between the age of those participants who completed to those that did not  $p=0.074$ .

The gender spread in the non-completer group; 3 female [3.5%] and 5 male [62.5%]. Chi-squared testing showed no significant difference in gender between those who completed and those who did not  $p=0.665$ .

Within the group of those not completing the programme, one declared Ethnicity as Asian, one was unknown and 6 were White.

All of those who did not complete had experience sleep problems for more than 12 months.

There was no significance between the number of interventions previously tried to manage the sleep problems and the likelihood of completing the programme.

#### *3.3.1 Reasons for non-completion*

Diagram 3 lists the reasons for non-completion of the programme.

*insert diagram.3*

From this it was identified that 63% of non-completions were not related to the service itself. In fact, reasons 1, 2, 7 and 8 achieved alternative positive outcomes as a result of engaging with the service. Reason 3 was outside of the control of the CSDS.

## **4.0 Analysis and Evaluation**

There are four key findings:

1. Positive Quality of Life impact for carers and family  $p=0.000$  CI[10.107, 41.464] df 13
2. There are identified advantages of the home based approach
3. The initiative met participant expectations and therefore had positive health outcomes for the child/young person  $p=0.003$  CI[-0.642, -0.548] df 13
4. The time spent and cost of this service can be cost-effective and efficient compared to melatonin use and Consultant based clinic appointments  $p=0.000$

The implementation of this Sleep Service had a significant and positive impact on parental and family unit quality of life. Despite parents reporting a wide variety factors that impact on this [not simply a

child's sleep problem], the support and service provided as part of this initiative has clearly impacted on the support felt by parents.

*"Parents say that they have found the process extremely helpful and do not feel helpless now as they know what to do"*

*"I would recommend this service to other families who are struggling. We knew we had to change things but didn't know how to...I have appreciated the support... home visits were the right approach for us"*

In addition, parents have expressed that home visits are the most appropriate approach in this instance. This enables staff to assess the home environment but also monitor how a family interact for bedtime routines which has a clear advantage over clinic based assessment. Home visits also enable staff to observe if advice and recommendations have been taken on board by parents e.g. changing wall colours in bedrooms, which could not be achieved by clinic based services. Even those participants who did not complete the programme still resulted in positive action for the child/young person by parents, service or both.

This Sleep Service has shown that it can meet participant expectations, therefore achieve positive health outcomes, and prepare parents/families/carers for on-going management of sleep disorders in children and young people. There are also some suggestions from qualitative responses that parents feel more prepared to deal with recurring or on-going sleep disturbances, highlighted the potential longer term impact of such a service.

Although approximate and for illustrative purposes only, this Sleep Service has shown that it could be cost effective and efficient in preventing the need for Melatonin, reducing the need for Consultant Outpatient Appointments and potentially impact positively on Community Paediatric waiting lists. In addition, by widening eligibility for the service by including children already prescribed Melatonin for example, this service could significantly reduce the associated cost to children's services in the locality. It is proposed that a 0.8WTE Band 4 AfC would effectively manage between 80-100 children per year with quantifiable and non-quantifiable cost savings and benefits [including service user satisfaction and experience]. Although only 22 were recruited in this project over 4 months, this would significantly be improved if the projects evaluation specific paperwork were not completed and, now that there are lessons learned with regard to efficient service design and delivery. A 0.8 WTE member of staff is recommended to support a service within the parameters of this locality and this proposal is over double the time allocated to this evaluation project. It is expected that wider implementation of this Sleep Service would potentially reduce Consultant/Community Paediatric referrals for sleep disorders and focus these specialised services to those children and young people with more complex needs, resulting in more efficiently managed Paediatric Community Services in the locality.

#### *4.1 Limitations & Lessons*

This was a small scale Sleep Service, implemented in community services to one locality in the East Midlands of the UK. The findings presented here are generalizable to the current service in this area only. However, they may be useful in informing the development of similar nurse-led services but also highlight a need for further robust research relating to home-based sleep hygiene services (NICE

& SCIE, 2013). Further research may examine similar interventions on a longer term basis, but possibly a cohort study or controlled trial may enable comparisons to be drawn between these types of interventions and current clinic based services. Furthermore, medium and long term cost-benefit analyses need to be considered to more strongly evidence the possible value to healthcare services.

Implementation and evaluation of similar services needs to be well organised and collaborative across the wider multi-disciplinary team. It was only with the support and confidence from the Consultant Paediatrics and Senior Management Teams that the service was funded and received referrals. In addition, the CSDS involved in the project found that monthly clinical supervision sessions were highly valued, particularly for non-professionally qualified staff.

## **5.0 Recommendations**

There are three key recommendations for practice:

- Nurse-led, home-based sleep services may be a cost-effective and positive method of provision to improve health outcomes and service user experience
- Further research into nurse-led, home-based Sleep Hygiene services is required in order to robustly evidence potential short, medium and long term impact and benefits, including cost-benefit analysis
- A service such as the one presented here may be effectively and feasibly staffed by a HCA/non-registered professional staff member, who is skilled, experienced and/or foundation degree qualified under supervision of a Lead Nurse with regular clinical supervision sessions to manage more complex cases

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